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Access to Oral Healthcare for People with Down Syndrome in the State of Connecticut

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Access to Oral Healthcare for People with Down Syndrome in the State of
Connecticut

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D.D.S. - University of Nuevo Leon-Mexico,1990

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Access to Oral Healthcare for People with Down Syndrome in the State of
Connecticut

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Table of Contents

| | | |
|------|---|----|
| I. | INTRODUCTION | 1 |
| II. | BACKGROUND AND GENERAL INFORMATION | |
| | Oral Health Status of People with Down Syndrome | 3 |
| | Access to Dental Care for People with Down Syndrome | 7 |
| | Past Studies of Access to Dental Care | 8 |
| | The Study Survey | 9 |
| III. | METHODS | 11 |
| | Data Analysis | 12 |
| IV. | RESULTS | 14 |
| V. | DISCUSSION | 22 |
| | Limitations | 24 |
| VI. | CONCLUSIONS | 26 |
| | Recommendation | 26 |
| VII. | REFERENCES | |
| | Appendix A | 28 |
| | Appendix B | 34 |
| | Bibliography of References | 35 |

List Of Tables

| | | |
|----------|---|----|
| Table 1: | Descriptive Characteristics of Socioeconomic Factors | 15 |
| Table 2: | Descriptive Characteristics of Access to Care and Utilization of Dental Services | 17 |
| Table 3: | Comparison of Time Since Last Treatment with Socioeconomic Factors | 19 |
| Table 4: | Comparison of Inability to Receive Care When Needed with Socioeconomic Factors | 20 |

List of Figures

| | | |
|-----------|--|----|
| Figure 1: | Race/ Ethnicity of Respondents | 16 |
| Figure 2: | Down Syndrome People's Regular Check-Up Rate | 18 |

Introduction

Down syndrome (DS) is a genetic condition caused by a chromosomal abnormality, which results in a characteristic appearance, learning disability, and a variety of physical, medical, and oral features (Roizen, 2003). Down syndrome occurs in one out of every 733 live births; more than 350,000 people in the U.S. have this genetic condition. Approximately 5,000 children with Down syndrome are born in the U.S. each year. Down syndrome affects people of all races, and economic levels (Davies, 2000). Literature from support and network groups such as the Connecticut Down Syndrome Congress, mentions that the number of newborn children with Down syndrome is estimated to be 36/year.

People with Down syndrome present a unique challenge for the dental community due to numerous factors: language impairment and overall limitation in communication between service provider and DS patient, limitations in social interaction and fear of new events/people/activities on the part of DS people, dental providers' awkwardness and lack of training, complex governmental requirements through Medicaid and other subsidies, and the additional costs incurred (including extra time needed) to address oral health issues for people with DS.

The objective of this study was to examine the experiences and expectations of caregivers of children and adults with Down Syndrome as they relate to their overall oral healthcare, and also other factors that may be affecting access to dental care.

A web-based survey was created for a specific group of caregivers, the results were recorded and analyzed, and some conclusions were drawn from the findings.

Background and General Information

Oral Health Status of People with Down Syndrome

While there is great variation among people with Down syndrome, those who are affected to a moderate or severe degree present more of a challenge to dentists than people with other handicapping conditions (Roizen, 2003).

Communication is the key to behavior management in dentistry, and when this is limited by any condition it makes comprehensive care more difficult.

The effects of oral disease can burden individuals throughout their lives. Nearly every American has experienced tooth decay, and children are especially susceptible to oral disease (Scully, 1976). National surveys report that around 7% of people with Down syndrome have unmet needs and that people with no insurance are 2.5 times less likely to receive dental care and 3 times more likely to have unmet dental needs (Hennequin, 1999). Almost a million children under the age of 6 and 4.5 million children between 6 and 16 years old fit the definition of being disabled (Chan, 1994). It was estimated that 8.1% of people with special needs had unmet dental needs in 1994 and 1995 (Gordon, 1998). Several studies reporting from the parent's perspective found that 13 to 75% of children with special needs had problems obtaining dental care (Allison, 2000; Bedi, 2001; Goldstein, 1988). Some of the barriers reported include difficulty with communication, excessive patient fear of unfamiliar people or settings, awkwardness of staff in dealing with a person with disabilities, financial disincentives, a need for sedation to complete dental care, having a severe

disability, dentists' not accepting Medicaid, and dentists' lack of knowledge and training (Edelstein, 2002).

These barriers have generally shown that dental health access for these individuals is poorer and their needs are greater than those without disabilities. One study found that 40% of caregivers experienced difficulty in locating a dentist willing to treat Down syndrome people despite the fact that 75% of the affected were cooperative enough to have dental treatment performed in the traditional dental setting (Newacheck, 2000).

Lack of access to dental care has a direct effect on overall health and quality of life. Chronic toothaches from decayed teeth, missing and loose teeth, chipped or fractured teeth, loss of supporting bone, dental abscesses, malocclusion, and misaligned teeth are conditions frequently observed in this population (Finger, 1989). Delay in the treatment of these problems eventually leads to more serious problems requiring more aggressive treatment which also increases treatment costs.

People with Down syndrome should have routine dental visits. This would allow for more familiarity with the environment and services related to oral care. Furthermore, it would assist with more positive reactions to conscious sedation, which frequently further complicate matters when problems are being addressed. Down syndrome patients often have atypical response patterns to pharmacological management, and standard doses and drugs are frequently ineffective (Brutner, 1990). In these cases, patients may need to undergo general anesthesia to have their treatment completed.

A better understanding of the dental community, benefits of frequent redundant dental visits, plus barriers that exist to prevent access to dental services are important factors in identifying opportunities for improvement in the oral health of this population. However, there was no identifiable research specific to the experience of caregivers of children and adults with Down syndrome in the State of Connecticut.

Caregivers of individuals with Down syndrome are often isolated, resulting in limited support and information necessary to enable them to access oral healthcare. (Edelstein, 2002). Also, physical and mental disabilities often make it difficult for special needs patients to visit health provider offices. Difficulty accessing dental offices can be largely attributed to two major obstacles: an inability to afford preventive and treatment related dental services and the limited number of dental professionals providing care to this population (Brutner, 1990).

Prejudice and assumptions have led to attitudinal discrimination by medical services towards individuals with disabilities. The shame of having a child with Down syndrome and the fear of being discriminated against have been shown to be even more disruptive of people's lives and well-being than the actual discrimination experienced (Gordon, 1998).

People with intellectual and physical disabilities have poorer oral health than the general population (Hagglund, 1999). Intellectually disabled people may require assistance or support from caregivers to maintain their oral health. The task of finding dentists who treat special-needs patients may be especially

challenging for people with limited literacy skills (McDermontt, 1986). Oral health for this population depends on the number of willing health care providers within the locality in which they live, and on the awareness of the caregivers about oral health issues.

With more than 1.5 million people with intellectual and physical disabilities depending on Medicaid for health care coverage, additional barriers to care include financing and funding issues such as Medicaid policies and administrative procedures, the number and location of dentists accepting Medicaid, and the value placed on oral health by patients' caregivers (Chambless, 1999).

Specialized care, such as sedation or general anesthesia, may be required because of the severity of oral disease or the patient's inability to cooperate with treatment. Because patients with intellectual disabilities often cooperate poorly with dental treatment, the therapy often has been extraction, resulting in a low number of restored teeth and a high number of missing teeth (Agili, 2001). This could also be viewed as a form of discrimination against Down syndrome people.

Despite the wide description of orofacial problems and their effects on individuals with Down syndrome and their caregivers, there is still little understanding of complex interaction of factors that influence their access to dental care (McDermontt, 1986). In most instances dental care for the patient with Down syndrome can be achieved with minor adaptations in the general practitioner's office. Although this population has some unique dental care needs, few patients require special facilities in order to receive dental treatment.

Adequate dental health care for people with developmental disabilities is a major unmet health need (Allison, 2001).

Access to Dental Care for People with Down Syndrome

Although it is recognized that children and adults with Down syndrome experience poorer oral health and have greater unmet oral health needs than the general population, they also have less access to screening and other oral health services than the general public. This happens despite The American Disability Act (ADA) Law of 1990 and other civil rights legislation designed to protect people with mental or physical disabilities from discrimination, and to provide public accommodations. The ADA set the agenda for a change in delivery of health care to people with a disability, emphasizing that disabled people have the right to equal access and standards of care as the rest of the general population.

Despite public policy protecting the disabled In addition, the U.S. Surgeon General's 2000 report on "Oral Health in America" cited significant disparities in access to dental care services for this population, even though they are at greater risk of developing oral diseases (Oral Health in America, 2000).

Access to healthcare continues to be addressed at the federal, state and local levels. The Healthy People 2010 initiative is a national effort to eliminate health disparities; several health goals have been set to be reached by 2010. The United States national government has already numerous regulations and standards relating to dental preventive care for American people with disabilities. The American Dental Association defines preventive dental care. as "oral health

supervision and anticipatory guidance, monitoring dental and oral growth and development; diagnosis and treatment of acute and chronic oral diseases.” A preventive dental care visit for people with Down syndrome should include all these components and also allow sufficient time for the dentist to provide proper oral health supervision.

The oral health needs of people with Down syndrome change with age, increasing as they get older (Reuland, 1986). The burden of preventive measures for this population falls on the family, the community, and the dental care providers.

For oral health providers, current knowledge of standards of care for people with Down syndrome is crucial, However, if dental care is to have any lasting impact, regular check ups are required. Appropriate interventions can then be suggested and monitored to guide caregivers and people with Down syndrome in the direction of good oral health.

Past Studies of Access to Dental Care

Studies investigating the oral health needs of people with learning disabilities indicates that they consistently have worse oral hygiene levels and a greater incidence of gingival inflammation and periodontal disease than the general population; they also experience more untreated diseases which cause more extractions (McDermott, 1986). Nevertheless, a recent study demonstrated a better clinical status for adults with learning disabilities than for the general

population. However they had fewer teeth, indicating that treatment was more likely to involve extraction (Reuland, 1986).

Other studies have examined access issues and found that people with disabilities have problems accessing oral health services and finding a dentist (Sjostrom, 1999). However, studies by Goldstein et al. and Allison et al. demonstrated that once children with Down syndrome found a suitable dentist, they were more likely to access regularly scheduled dental services than their non-Down syndrome peers. Despite this, the latter study also showed that in terms of frequency they are less likely to receive treatment than their non-Down syndrome peers.

Most of the literature detailed thus far pertains to individuals with general learning disabilities. Down syndrome is a unique condition within the spectrum of learning disabilities, and individuals with Down syndrome have a range of experiences that differs that of other groups with learning disabilities as well as the non-disabled population (Allison, 2001).

The Study Survey

This study will examine the role of caregivers on the barriers encountered in trying to access oral health care for people with Down syndrome within the state of Connecticut. An assumption was made that caregivers' knowledge of preventive dental care is another factor that will impact access and that it should be measured. If caregivers are not familiar with the guidelines for preventive dental care, then understandably they cannot conform to the established guidelines. Clearly, numerous variables may influence access to dental healthcare

and have implications for chronic oral health conditions among children and adults with Down syndrome. Several of these variables work independently, while other variables have a combined effect.

We selected the Connecticut Down Syndrome Congress (CDSC) as our target caregivers. The CDSC is a non-profit organization, founded in 1986. It promotes opportunities and inclusion for people with Down syndrome. Its mission addresses advocacy, support, promotion of public awareness and overall encouragement to quality services for people with Down syndrome.

By assessing responses within the Connecticut Down Syndrome Congress community, this study should provide valuable information about oral health care of children and adults with Down syndrome. This study should also provide information about problems encountered with access and caregivers understanding of their children and adults' oral health and oral health care needs. Our findings have the potential to help improve the quality of oral healthcare for people with Down syndrome in the State of Connecticut.

Methods

Data for this study was collected through a survey instrument that targeted caregivers with children and adults with Down Syndrome aged one and up.

Since people with Down syndrome are usually not independent individuals, the majority of the oral healthcare responsibility falls upon the caregivers such as parents and legal guardians. Caregivers of this group are the ones responsible for obtaining dental insurance, scheduling dental appointments, and bringing their Down syndrome children or adults to their dentists. Therefore, it is likely that the caregivers' own beliefs about dental care are an important factor in understanding the access to oral healthcare among the Down syndrome population.

A web-based survey was e-mailed to 200 members/caregivers from the Connecticut Down Syndrome Congress (CDSC) in the month of March of 2008. The survey included a cover letter from the CDSC president (Appendix B) and a web link to the online questionnaire which was hosted by Survey Monkey (<http://www.surveymonkey.com/>). The president of the CDSC invited the members to participate in the local newsletter that each member received; CDSC members were asked to respond within two weeks. The caregivers were informed that their responses would be completely optional, anonymous, and confidential.

The 37- item structured questionnaire was designed to collect information about caregivers' experiences with and expectations of oral healthcare for their family members with Down syndrome. The questionnaire included the following sections:

Demographic information

Experience with dental treatment

Desirable qualities of dentists

Information requirements

Access to dental services

The questions were primarily in multiple choice and Likert Scales format.

Likert Scales are commonly used to “quantify attitudes and domains of health-related quality of life” (Sjostrom, 1999). On the Likert Scale items, respondents reacted to statements on access to dental care and beliefs about dental care providers, according to the degree of their beliefs on a scale of 1 to 5 (1=Strongly agree, 5=Strongly Disagree).

Prior to distribution, the survey instrument was reviewed by two faculty advisors, a Community Health Center dental director, and a caregiver for a child with Down Syndrome (who is not member of the CDSC). Items were revised based on their input.

Data analysis

The data were entered into an Excel spreadsheet and transferred to SPSS Version 12, which was used to calculate frequencies, associations and statistical significance (Appendix A). Chi-square was used to determine level of association.. Bivariate analysis was used for most associations.

Ethical approval

Ethical approval for the study was granted by the Institutional Review Board (IRB) at University of Connecticut Health Center.

Results

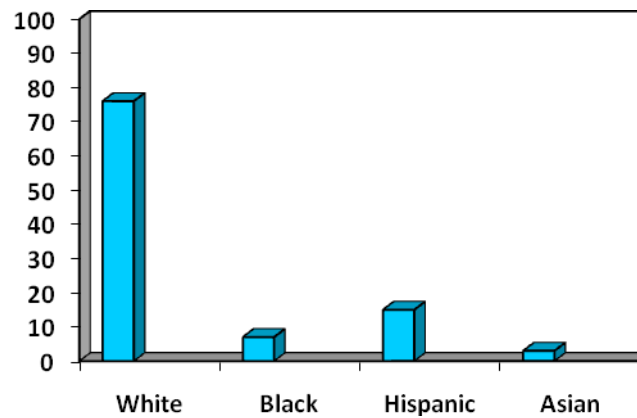
Characteristics of the respondents

From the 200 electronically distributed web surveys, 76 were completed, resulting in an overall response rate of 38%. Although 3% of the questionnaires were incomplete, the data that they contained was nevertheless considered useful and included in the analysis of the relevant variables. Respondents' ages ranged from 25 to 66 (mean=45 years old) and 48% were over 39 (Table 1). The majority of respondents (73%) were white (Figure 1). and female (82%), with incomes between \$35,000 -\$74,999 (62%). Fourteen per cent reported household incomes lower than \$34,000 and 24% reported incomes more than \$75,000. The education level of respondents was almost evenly distributed among those who had received only a high school education (25%) and those who had received an associate's degree or higher education (26%). Most of the caregivers had some college education (47%). Sixty-two per cent of respondents were parents of a child or adult with Down syndrome, 24% were legal guardians, and 9% step-parents (Table 1).

Table 1 Caregiver Socioeconomic Characteristics

| Socioeconomic Characteristics | N | Percent |
|--------------------------------------|----------|----------------|
| Insurance Type | | |
| Private | 34 | 45 |
| Public | 18 | 24 |
| Medicaid (Title19) | 22 | 29 |
| Age (years) | | |
| 25-39 | 36 | 47 |
| 40-66 | 37 | 49 |
| Sex | | |
| Male | 13 | 17 |
| Female | 59 | 78 |
| Race | | |
| White | 58 | 76 |
| Black | 5 | 7 |
| Hispanic | 11 | 15 |
| Asian | 2 | 3 |
| Education | | |
| 11 th grade or Less | 1 | 1 |
| High School Diploma | 18 | 24 |
| Some College | 35 | 47 |
| Associate degree | 2 | 3 |
| Bachelor degree | 9 | 12 |
| Postgraduate degree | 9 | 12 |
| Household Income | | |
| Less than 10,000 | 1 | 1 |
| 10,000 - 19,000 | 0 | 0 |
| 20,000 - 34,999 | 9 | 13 |
| 35,000 - 49,999 | 22 | 31 |
| 50,000 - 74,999 | 22 | 31 |
| 75,000 - 99,999 | 7 | 10 |
| 100,000 or more | 10 | 14 |

Figure1. Race/ Ethnicity of Respondents



Characteristics of the Down syndrome people

Family members with Down syndrome ranged in age from 2 to 52, with 76% between 2-19, year's old and 24% between 20-52 years old. The majority (76%) were white, while the other was Hispanic (15%), Black (6%), and Asian (3%).

Access to Dental Services:

Among the family members with Down syndrome, 97% had a regular source of dental care and 79% received care regularly (more than once a year), as shown in Figure 2. This dental utilization pattern reflects that of their caregivers: 50% of the caregivers were also receiving regular dental care and 30% had been to see their dentist within the past year. Finding a dentist was identified as a problem with 73% of caregivers reported encountering difficulty in finding a dentist. Travel time was a challenge for 16% of caregivers, who reported that it took them more than one hour to get their disabled family member to the dentist.

A little more than half (52%) of the caregivers had to travel between 30-60 minutes, while 32% had to travel less than 30 minutes.

When respondents were asked what type of dental care provider their children or adults with Down syndrome saw at their last dental appointment, 16% reported a visit to a general dentist. 12 of the 16% were of age under 19, while the other 4% were over 19 years of age. Most of the DS population 75%, received dental treatment from a pediatric dentist on one or more occasions, where 63% represented children under 19 years old, the other 12% are DS people over 19 years old. (Table 2)

Table 2. Child/Adult with Down syndrome Access to Care and Utilization of Dental Services.

| Access Characteristics | N | Percent |
|--|----|---------|
| Dentist for periodic oral healthcare | | |
| Yes | 72 | 97 |
| No | 2 | 3 |
| Type of provider | | |
| General dentist | 12 | 16 |
| Pediatric dentist | 56 | 75 |
| Oral surgeon | 3 | 4 |
| Dental hygienist | 3 | 4 |
| Travel Time | | |
| Less than 30 minutes | 24 | 33 |
| 30 minutes to 1 hour | 37 | 51 |
| 1 to 2 hours | 11 | 15 |
| More than 2 hours | 1 | 1 |
| Unable to get care when needed in past year | | |
| Yes | 6 | 8 |
| No | 65 | 87 |
| Don't know | 4 | 5 |

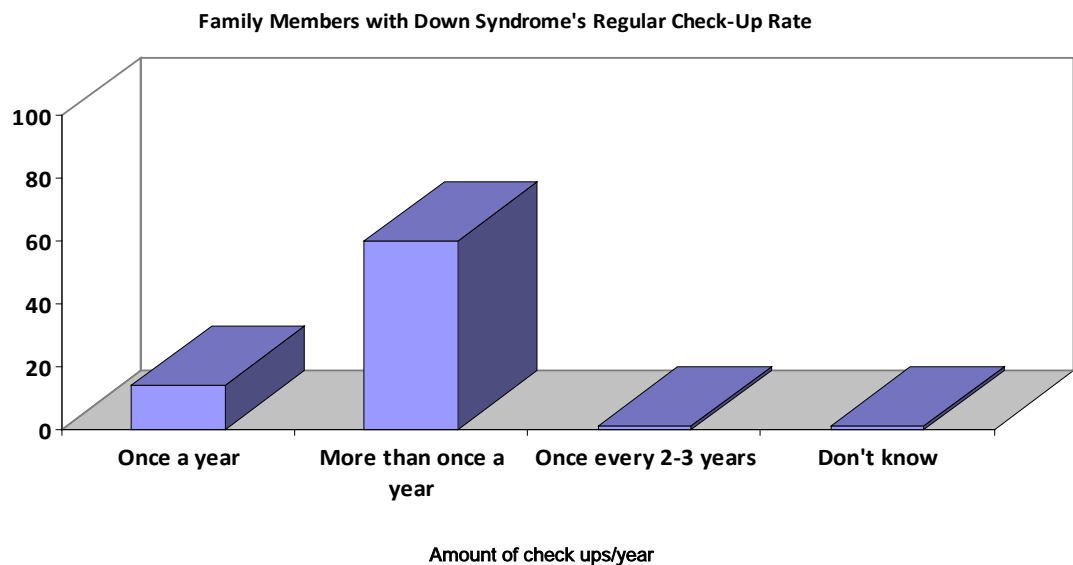


Figure 2. Down syndrome people's Regular Check-Up Rate

The survey question about access to oral healthcare was, “Does your child or adult with Down syndrome have a dentist for regular oral health care?” When results were analyzed by insurance type, age of family member and education level of caregiver, more than 95% of family members with Down syndrome had a dentist for routine dental care. Because of the high level of access, there were no significant differences in access.

Age, education, income, and type of insurance were analyzed using chi square to determine their effect on the ability to obtain dental care when needed and time since last dental treatment (Tables 3, and 4). Of all the variables, only “Type of dental insurance” produced statistically significant results ($p > .05$). “Age”, “Education” and “Household Income” all were not found to have significant results, $X^2 3.242$, $p = < .10$. Other analysis was performed without producing any significant results on the following data:

1. D.S family members' dental care status by health insurance type
2. Caregivers' dental care status by education level of caregivers
3. How often should D.S family members go to dentist by Ages of D.S family members
4. How often should caregivers go to dentist by household incomes
5. Travel time by ages of D.S family member
6. Dental provider type by education level of caregivers

Table 3 Time Since Last Treatment by Socioeconomic Factors

| Socioeconomic Characteristics | The last time you child Received dental care % | | | | | p-value |
|-------------------------------|--|-------|--------|--------|--------|---------|
| | N | 6 mos | 6-1 yr | 1-2 yr | 2-4 yr | |
| Insurance | | | | | | .001 |
| Private | 32 | 75 | 19 | 6 | 0 | |
| Public | 40 | 28 | 40 | 20 | 13 | |
| Age Caregivers | | | | | | .408 |
| Under 39 years | 35 | 43 | 40 | 11 | 5 | |
| Above 39 years | 37 | 54 | 22 | 16 | 8 | |
| Education | | | | | | .206 |
| Low education | 19 | 4 | 15 | 0 | 0 | |
| High Education | 55 | 9 | 44 | 1 | 1 | |

Table 4 - Comparison of Inability to Receive Care When Needed with Socioeconomic Factors

| Socioeconomic Characteristics | Within the last year, was there a time when your child needed dental care but was unable to get it? | | | |
|---------------------------------|---|-------|------|---------|
| | N | % Yes | % No | p-value |
| Insurance | | | | .027 |
| Private | 33 | 3 | 97 | |
| Public | 36 | 11 | 89 | |
| Age Down syndrome people | | | | .086 |
| Under 19 years old | 57 | 5 | 95 | |
| Above 20 years old | 14 | 21 | 79 | |
| Income | | | | .072 |
| Low Household Income | 28 | 14 | 2 | |
| High Household Income | 39 | 3 | 97 | |

Experience of dental treatment:

When caregivers were asked questions about their experiences with dental treatment for their family members with Down syndrome, 96% responded that they experienced preventive treatment. Over half (53%) had been told by a dentist that they had tooth decay and 42% had gum disease. Caregivers were asked to indicate the reason why their child or adult with Down syndrome was not scheduled for routine dental care during the last year by checking all the statements that applied (so total percentages exceed 100%). Most caregivers (76%) said that the biggest barrier to routine dental care during the last year was the inability to find a dentist with special skills or willingness to treat people

having disabilities. Other reasons included, “my child or adult with Down syndrome doesn’t want to go to the dentist (51%),” and “there was no dental service available in my area” (46%); 35% said that transportation or work related issues were a problem.

Desirable qualities of dentist

Most caregivers (76%) felt that dentists should have special skills and willingness to treat people with Down syndrome. This preference was supported by actual behavior with 75% of caregivers taking their children to specialised providers; Seventy-five percent had received dental treatment from a pediatric dentist on one or more occasions. Only 16% of the individuals with Down syndrome were receiving care from a general dentist.

Information

Only 20% of the respondents reported being counseled about preventive dental care by other healthcare professionals (doctors, nurses, physician’s assistants). Most of the caregivers (59%) felt that speaking to the dentist was the most useful way of learning about prevention and treatment of oral health problem related to Down syndrome.

Discussion

This paper reports the findings of a quantitative study of the experiences and expectations of caregivers of children and adults with Down syndrome the paper looked at both oral health issues and factors related to accessing dental care. The results of this study are of relevance because it is estimated that up to 80% of adults with Down syndrome now live to 55 years of age or more (Roizen, 2003).

The high levels of access to dental care and regular dental attendance reported by caregivers in this survey are extremely encouraging. Almost all (92%) of the family members with Down syndrome had a regular source of dental care and 79% reported regular dental visit (more than once a year). This is also a reflection of the dental utilization behavior of their caregivers (50% had regular dental visit), while only 20% had not seen a dentist for more than one year. However, caution should be exercised when interpreting the results as other studies of people with learning disability have reported greater problems in accessing oral health services (Newacheck, 2000) although the study by Allison et al, 2000 was conducted in France and the other studies were published more than a decade ago before the Americans With Disabilities Act came into effect. It could also be argued that members of the CDSC are not representative of all caregivers of children and adults with Down syndrome as they are probably the most motivated of such caregivers. Therefore, they are more likely to be aware of the needs and rights of the those with Down Syndrome in their care. It is difficult to obtain a representative sample of children and adults with Down syndrome as there is no national or local database and not all children and adults with Down

syndrome are known to social services agencies or belong to advocacy and support organizations.

Furthermore, the sample size was small in relation to the likely number of the children and adults with Down syndrome in the state of Connecticut, also threatening the validity of the findings. It was not possible to arrange a second electronically mailing to improve the response rate although a response rate of 30-40% is regarded normal for web questionnaire surveys and it is reasonable to present the results as representative of the views of the target group. However, the non-respondents are more likely to be people who were not interested in and/or did not use dental services, introducing a positive bias into the results. Thus interpretation of the quantitative data should be carried out on the basis that this is the best scenario for this group of parents/children.

The study suggests and supports that a number of different factors may influence caregiver and people with DS experiences of oral healthcare. These include the attitudes and skills of dental health professionals, stigma, caregivers' own oral health beliefs and practices, their expectations of dental care for their family member with DS, and level of information and support received from dental providers. Similar factors have been identified in other studies of people with learning disabilities (Chan, 1994; Gordon, 1998).

Providing quality dental care to individuals with Down syndrome requires a supportive, skilled dental team (Hagglund, 1999) in combination with time and patience. In this study, the majority of individuals with Down syndrome were being treated in specialty practices. The current dental insurance payment

mechanisms tend to dissuade dentists from spending the extra time necessary for good communication and behaviour management. However access to quality dental services did not appear to be particularly a problematic this for this group of patients, as most of their caregiver carried private insurance.

It is apparent that there is still a considerable lack of information given to parents about oral health issues pertaining to Down syndrome by dentists and other health care providers. While most caregivers felt that informational pamphlets would be helpful and should be made available from a variety of sources, this and other studies indicate that it is equally important for parents to receive support from concerned health professionals who are sensitive enough to provide appropriate and timely information (Newcheck, 2000). Consequently, caregivers in the current study appear to expect dentists to actively collaborate with other health care professionals in providing information about oral healthcare.

Limitations

There were several limitations to this study. The most salient of these is that the target population was not reached. Fewer than 20% of the respondent population consisted of minorities (Figure 1) and the educational level was high, as most respondents had completed college. Therefore, the respondent population is not representative of the state of Connecticut. This lack of diversity suggests that the CDSC membership has a high ratio of educated and insured Caucasian members. Unfortunately, the survey did not track town or zip code, so no

determination can be made as to the residence location of the majority of the respondents.

Conclusions

This survey does confirm what has long been known. The educated, middle-class population generally follows the guidelines for preventive dental care for their children and adults with Down syndrome.

Caregivers with household income between \$20,000-\$49,000 may be a vulnerable group in between public assistance and private insurance.

Seventy three percent of the sample indicated had difficulty identify a dentist with special skill or willingness to work with people having disabilities.

Pediatric dentists are treating the majority of these special need population.

Recommendations

Although this survey did produce some useful data, there are still many unanswered questions. One of these is how ethnicity, race, insurance and socioeconomic status affect access to dental care, especially for the Down syndrome population. Because CDSC did not represent the general population, findings can only be extrapolated to the CDSC membership, not to all caregivers for Down syndrome people in the state of Connecticut.

For a thorough analysis of the State of Connecticut Down syndrome population, a method needs to be designed that will target those with lower socioeconomic status. One way to do this would be to collaborate with the State Department of Social Service and conduct a phone survey in a few towns, including Hartford, which will allow direct contact with the respondents.

Financial incentives may also help target the lower socio economic population. Obtaining data from this population would be pertinent in truly defining the degree to which access to dental care is impaired in the state of Connecticut particularly for the disabled population.

It will also allow for a deeper understanding of the problems of access to healthcare among this population. If the population is found to have significant barriers for access to dental care, then it can be determined whether this affects the rise in oral diseases among children and adults with with Down syndrome in Connecticut.

Appendix A: Demographics, Health Care and Utilization, Child and Adult with Down Syndrome Health Status. Caregivers Relationship and Health Belief-Frecuencies.

For this survey if you have more than one person with Down syndrome in your household, please answer for the youngest child or adult.

1. What is your child or adult's with Down syndrome race?

- ☐ White , Non- Hispanic
- ☐ Black , Non- Hispanic
- ☐ Hispanic
- ☐ Asian /Pacific Islander
- ☐ Other _____

2. Please indicate the age of the child or adult with Down syndrome you will be answering questions about: _____ years

3. How many children or adult with Down syndrome (1 year old or older) are in your household?

- ☐ 1 child
- ☐ 2 children
- ☐ 3 children
- ☐ 4 children
- ☐ 5 children or more

4. What type of health insurance does your child or adult with Down syndrome in your care have?

- ☐ Private (AETNA,BCBS,Connecticare)
- ☐ Public (PHS,HUSKY,A/B,CHN)
- ☐ Medicaid (Title 19)
- ☐ Self-insured
- ☐ Uninsured
- ☐ Don't know

5. Does your child or adult with Down syndrome have a dentist for periodic oral health care (that is, examination, preventive procedures, and routine treatment)?

- ☐ Yes
- ☐ No

6. Where do you take your child or adult with Down syndrome for dental care?

- ☐ Dentist's offices
- ☐ Dental School
- ☐ Health Center
- ☐ Emergency departments
- ☐ Hospital - dental clinic
- ☐ Other (please list): _____

7. On average, how often does your child or adult with Down syndrome visit a dentist for regular check-ups?

- ☐ Once a year
- ☐ More than once a year?
- ☐ Once every 2-3 years?
- ☐ Don't know

8. Has your child or adult with Down syndrome ever been admitted to the hospital emergency room due to a dental problem?

- ☐ Yes
- ☐ No
- ☐ Don't know

9. Have you ever been told by a dentist that your child or adult with Down syndrome has any of the following? (**Please check all that apply**)

- ☐ Tooth decay
- ☐ Gum disease
- ☐ Mouth infection
- ☐ Loose teeth
- ☐ Large tongue
- ☐ Small teeth
- ☐ Missing teeth
- ☐ Bleeding gum

10. What do you think of your child or adult's with Down syndrome oral health status?

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor

Please rank in order of importance (1= extremely important, 2= very important, 3=somewhat important, 4=not very important, 5= not important at all) reasons why routine dental care did not occur for your child or adult with Down syndrome during the last year.

11. Long wait in the waiting room. ☐1 ☐2 ☐3 ☐4 ☐5
12. Transportation /Work ☐1 ☐2 ☐3 ☐4 ☐5
13. Insurance/ Payment ☐1 ☐2 ☐3 ☐4 ☐5
14. There are no dental services available in my area of the state ☐1 ☐2 ☐3 ☐4 ☐5
15. Other child/adult care responsibilities ☐1 ☐2 ☐3 ☐4 ☐5
16. My child or adult with Down syndrome doesn't want to go to the dentist. ☐1 ☐2 ☐3 ☐4 ☐5
17. I cannot find a dentist with special skill or willingness to work with people having disabilities(i.e., Down syndrome) ☐1 ☐2 ☐3 ☐4 ☐5

Please answer the following items on a scale from 1 to 5 (1=Strongly agree; 2= Agree; 3= No Opinion ; 4= Disagree; 5=Strongly Disagree):

18. I feel comfortable telling my child or adult's with Down syndrome dental care provider about his/her medical concerns. ☐1 ☐2 ☐3 ☐4 ☐5
19. My child or adult's dentist listens to what I have to say about my child or adult's with Down syndrome health and answers my questions. ☐1 ☐2 ☐3 ☐4 ☐5
20. My child or adult's with Down syndrome dental care provider explains medical and dental information to me. ☐1 ☐2 ☐3 ☐4 ☐5
21. Within the last year, was there a time when your child or adult with Down syndrome needed dental care but was unable to get it?
- ☐ Yes
☐ No
☐ Don't know

22. When do you take your child to the dentist?

- ☐ Only when he /she is sick in pain (toothache)
- ☐ For regular check-ups
- ☐ Only when I have medical/dental question or concern about mychild's oral health.
- ☐ Sometimes when my child or adult with Down syndrome is not in pain but I think he/she should go.
- ☐ Other _____

23. How often do you think your child should go the dentist for a regular check-up?

- ☐ More than once a year
- ☐ Once a year
- ☐ Once every two years.
- ☐ Once every three years.
- ☐ Never if he/she present no dental problem

24. How difficult is it for you to locate a dentist who will treat your child?
(please check one)

- ☐ Cannot locate one
- ☐ Very difficult
- ☐ Somewhat difficult
- ☐ Somewhat easy
- ☐ Easy

25. How much time did it take for you to travel to your child or adult's with Down syndrome most recent dental visit? **(please check one)**

- ☐ Less than 30 minutes
- ☐ Between 30 minutes to 1 hour
- ☐ Between 1 and 2 hours
- ☐ More than 2 hours

26. Do you know what type of dental care provider your child or adult with Down syndrome saw last dental visit? **(please check one)**

- ☐ General dentist
- ☐ Pediatric dentist
- ☐ Oral surgeon
- ☐ Dental hygienist only
- ☐ Don't Know

27. Your Age:_____ years

28. What is your sex ?

- ☐ Male
- ☐ Female

29. What is your relationship to the child in question? **(please check one)**

- ☐ Parent
- ☐ Stepparent
- ☐ Legal guardian
- ☐ Other (please list)_____

30. What is your race /ethnicity?

- ☐ White , Non- Hispanic
- ☐ Black , Non- Hispanic
- ☐ Hispanic
- ☐ Asian /Pacific Islander
- ☐ Other _____

31. What is your current employment status? **(please check one)**

- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Unemployed looking for work
- ☐ Retired
- ☐ Homemaker
- ☐ Student
- ☐ Other (please list):_____

32. Including all sources of income, please indicate your approximate household income in 2007, before taxes:

- ☐ Less than \$ 10,000
- ☐ \$10,000 - \$19,999
- ☐ \$20,000 - \$34,999
- ☐ \$35,000 - \$49,999
- ☐ \$50,000 - \$74,999
- ☐ \$75,000 - \$99,999
- ☐ \$100,000 or more

33. What is the highest level of school you completed? (**please check one**)

- ☐ 11th grade or less
- ☐ High school diploma
- ☐ Some college
- ☐ Associate degree
- ☐ Bachelor degree
- ☐ Postgraduate degree

34. Where have you heard/seen the term preventive dental care?

- ☐ I have not heard this term.
- ☐ From my dentist
- ☐ From another health care worker
- ☐ From a family member/ friend
- ☐ Other parent of people with Down syndrome
- ☐ Charity Organizations
- ☐ Media, internet
- ☐ Other _____

35. Please indicate the last time you received dental care from a dentist?

- ☐ Has not received dental care
- ☐ within the last 6 months
- ☐ 6 + months to 1 year ago
- ☐ 1 + to 2 years ago
- ☐ 2 + to 4 yaers ago
- ☐ Over 4 + years ago
- ☐ don't know

36. Why do you usually visit to the dentist?

- ☐ Only when I'm in pain
- ☐ For regular check-ups

37. What was the reason for your last dental visit?

- ☐ Preventive
- ☐ Preventive and treatment
- ☐ Treatment
- ☐ Never visited dentist/more than five years since last visit

Appendix B: Cover Letter E-mail out with Study Survey

Dear Member of the CT Down Syndrome Congress,

Survey Study Title:

Access to Oral Healthcare for Children and Adult with Down Syndrome, Caregiver's Survey

This survey was designed to address the factors affecting access to dental care for people with Down syndrome. The information we are trying to collect will be used to develop the appropriate community/dental providers education programs for this population if needed. Additionally, we are interested in learning how much information you have received about dental care, and your expectations regarding access to oral health care.

This is a completely optional and anonymous survey. You may skip any question that makes you feel uncomfortable. We do not ask for your name, phone number, or any contact information

Please complete the survey within 2 weeks of receiving it, and return it by e-mail. Your completion and return of the survey implies consent.

The survey will only take a 20 minutes; your response is greatly appreciated.

Thank you for your help.

Sincerely,

Principal Investigator:

Judy Lewis, M.Phil 860- 679-3458

Graduate Student Researcher:

Moises Salas, DDS 860- 593-2667

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